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Patients, Prescribing & Personalised Pharmacy: Innovations and Opportunities

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Patients, Prescribing & Personalised Pharmacy

Innovations & Opportunities

Claudia Pagliari PhD FRCPE

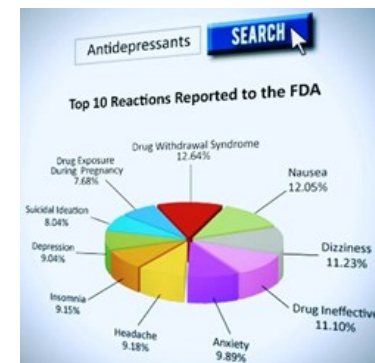
Director, Global eHealth Programme
Usher Institute for Population Health
Sciences & Informatics
Farr Scotland
ADRC-Scotland

How might ePharma research impact the patient experience?

- **Data linkage for scaled validation of clinical trial results**
 - Real world intelligence for iterating guidelines & translational R&D
- **Identifying signals of actual and potential ADEs**
 - Early drug withdrawal or reformulation
 - Reduced patient discomfort & risk, better QoL
 - Understanding patient mediators for better stratified prescribing
- **Demonstrating effects of Polypharmacy in natural experiments**
 - Interactions not yet causing harm
 - Serendipitous associations
- **Linking primary care prescribing data with clinical data**
 - Informing personalised & stratified treatments
- **Cost effective analytics**
 - Cost-effective prescribing
 - Value proposition for society

Detecting Adverse Drug Reactions

- ADRs -> 5-30% of hospital admissions in US, Australia, Europe
- Tip of the iceberg, many go unreported
- RCTs poor detectors. Small samples. Unrealistic controlled settings. Few opportunities to examine behavioral and patient modifiers. Not powered to detect micro effects.
- Scaled clinical data linkage holds great potential, and pharmacovigilance is the most advanced application of these methods so far
- But this is only part of the story...
- Patient reported ADRs hold promise
 - What are the best ways to do this?



Mobiles & Clinical Trial Coordination

Pharmaceutical industry investing in mobile platforms for trial coordination & data management

Potential to speed translation to innovations for patient care

Companies springing up to fill this gap

Mostly data collection platforms, mobile form submission, updating protocols

Moving towards patient-reported outcomes ...



Online awareness raising

- 75% of people unaware of clinical studies
- Around half of all trials don't fill their recruitment quotas
- Not just scientists 'pushing' risky trials to patients
- Many patients want and seek engagement
- But risks of suggesting that 'experimental' is better



Dr Claudia Pagliari @EeHRN · Apr 27

Drug companies investing in eHealth to raise trial recruitment. But do they really understand patient motivation?

forbes.com/sites/zinamouk...



TrialReach

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A Clinical Trial For People with Previously Treated Stage IV Non-Small Cell Lung Cancer

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[Eligibility](#)

[Logistics](#)

[Trial drug](#)

[Background](#)

[Contact](#)



Dr Claudia Pagliari @EeHRN · Mar 25

Why isn't pharma harnessing patients' desire to monitor biomarkers & providing tools for interpretation? [#mctcongress](#)

[@JackWhelan](#)



[View photo](#)

Direct-to-patient trial recruitment

“After six hours, we have 7,406 people enrolled in our Parkinson’s study. Largest one ever before was 1,700 people” (Tweet from Parkinsons app developer, May 2015)

Stanford Uni cardiovascular trial attracted 11,000 volunteers in one day after releasing their ‘MyHeart Counts’ App in the App Store. It would normally take a year to enroll that many subjects (*Bloomberg Business*, March 2015)

Early days. Sampling challenges (noise, representativeness), but great potential....

ResearchKit: a clever tool to gather clinical data

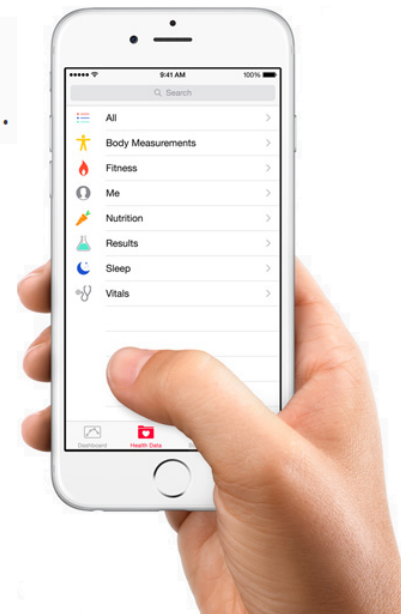
The Pharmaceutical Journal |, 7 MAY 2015 | By Dara Mohammadi

New software from Apple makes it easy for iPhone users to contribute to medical research but scientists warn there may be pitfalls.

You’re already carrying a powerful medical research tool.



ResearchKit



Clinical Trials & Data Quality

Patient Recruitment

Expense & inconvenience limit numbers & generalizability. Recruiting via apps could open up a population of potential trial participants. 700 million iPhone users

Data Objectivity

Trial data can be subjective (e.g. symptom ratings) & clinical data can be flawed. ICT can generate quantifiable metrics e.g. exercise (actigraphy), biomonitoring (embedded sensors & linked peripherals), self-report tools etc. May reduce false reporting by patients

Data Frequency

80% - 90% of iPhone users keep them within arm's length 27/7. *"We're trying to change the scale of the data that we can collect, from data collected every three months, to every second."* Apple Executive, quoted in *Forbes Business*, March 9th



Data quality – *"Many Carbon Monoxide poisonings may have been intentional rather than accidental, raising questions for national reporting (Miller, Pagliari et al, IoM, 2011)"*



Download Our Cancer Clinical Trials App Today

Search for trials by disease, phase, physician, or location on your Apple or Android device.



The new wearables

Linked to HealthKit, the Apple Watch can track blood glucose, heart rate, blood pressure, exercise and much more. Being portrayed as everything from a personal lifestyle checker to a cure for cancer.



“Google X is building a wearable health sensor for cardiac and activity tracking, but it isn’t a Fitbit or Apple Watch competitor: Google’s device is a clinical-grade sensor designed for investigational use” MobiHealthNews, June 23rd

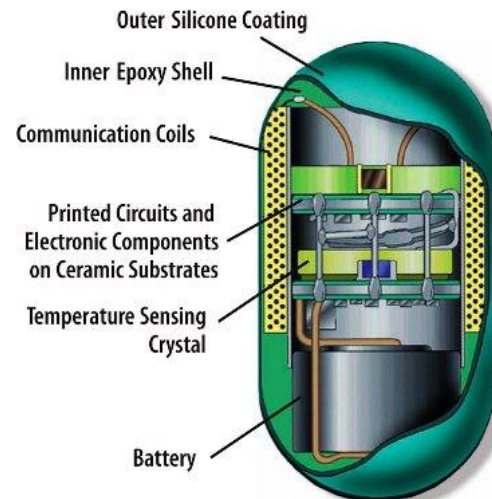


Home-based telemonitoring is gaining traction but mHealth is the future

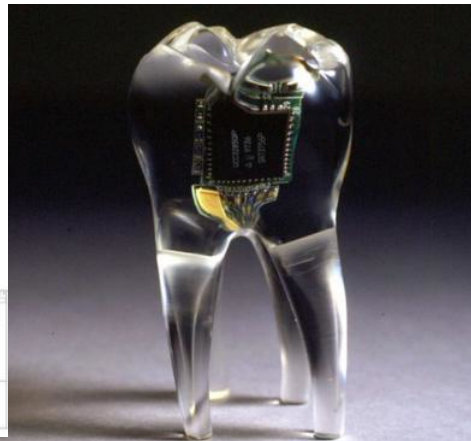
Coming soon

Proteus Ingestible Sensor for Tracking Medication Intake Receives FDA Clearance

by WOUTER STOMP on Jul 31, 2012 - 1:42 pm

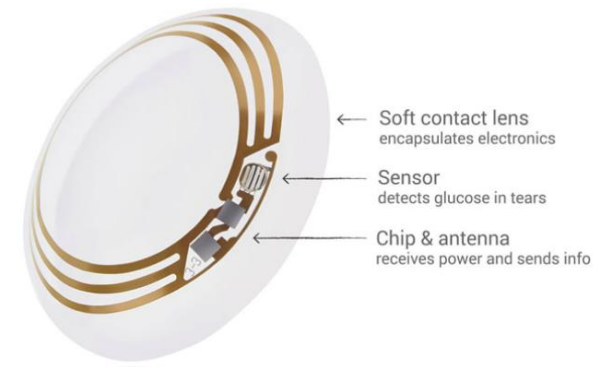


Google-Novartis Diabetes Monitoring Contact Lens Patented Jan 2015. Others following e.g. Medella Health



Radboudumc

„Insideables”



Digital Phenotype

The data captured as we interact with digital technologies and services, have potential to provide a phenotypic footprint, useful for research, diagnostics, prognostics and personalised medicine

Multiple channels:

- Web searches
- Social media
- Mobile apps
- Wearables
- Smart homes
- Internet of Things
- TV habits, Shopping etc.

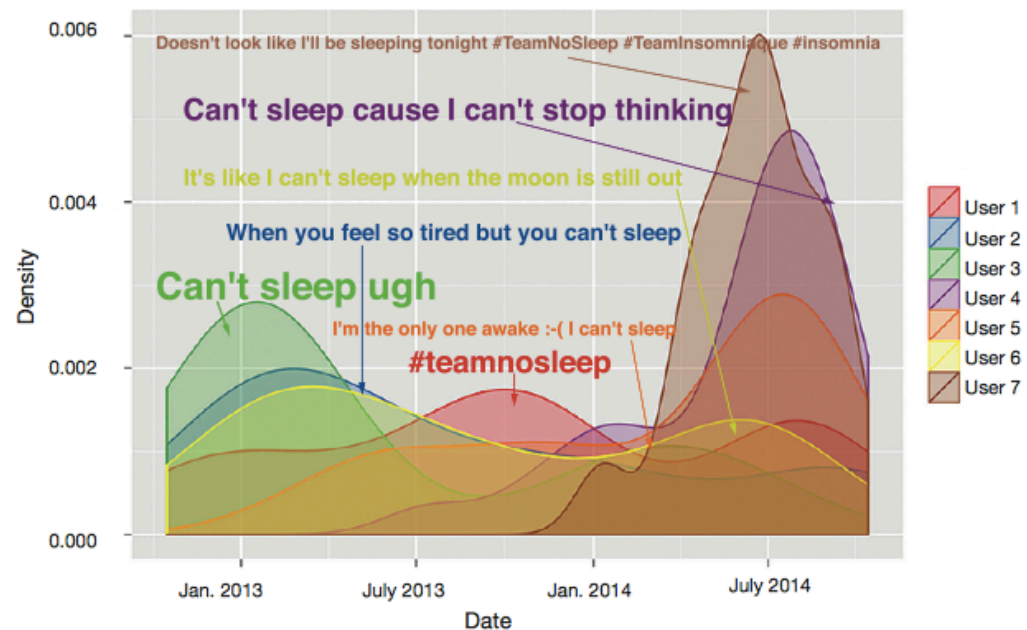
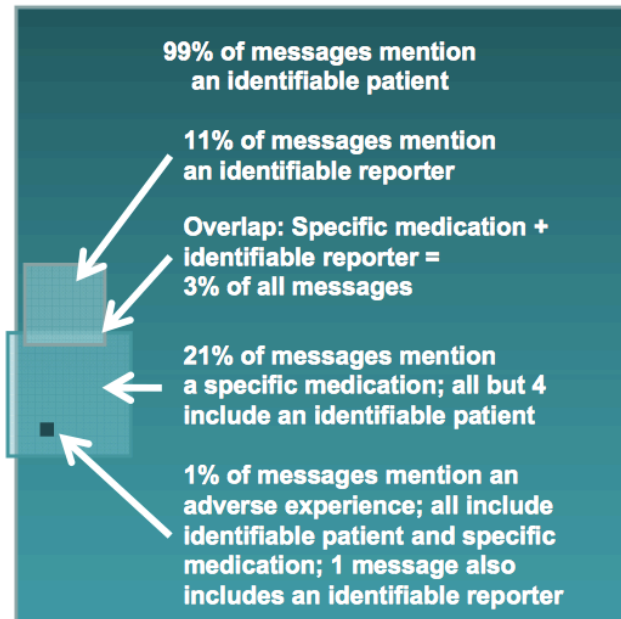


Figure 1 Timeline of insomnia-related tweets from representative individuals. Density distributions (probability density functions) are shown for seven individual users over a two-year period. Density on the y axis highlights periods of relative activity for each user. A representative tweet from each user is shown as an example.

Jain et al May 2015. *Nature Innovation*

New Responsibilities for Govt & Pharma?

- Nielsen BuzzMetrics' analysis of 500 messages shows that just 1 message meets all four reporting criteria.
- Adverse experiences are uncommon in CGM discussion, occurring in just 1% of messages.




Among 500 messages scored, 1 message incorporates all four reporting criteria

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EFPIA targets MEPs in social media campaign

Published on 08/09/14 at 08:17am



The MHRA has announced that it is to lead European medicines regulators, academics and pharma in a three-year project to develop new ways of gathering drug safety information.

Known as 'WEB-RADR', the project is in response to the rise in the use of smartphones, apps, and social media for discussing issues with medicines and health, says the MHRA.

the
PHARMACEUTICAL JOURNAL
A Royal Pharmaceutical Society publication

Searching social networks to detect adverse reactions

Looking to communities for innovative research

Data for good



Your data has a heartbeat that gives new life to medical research.

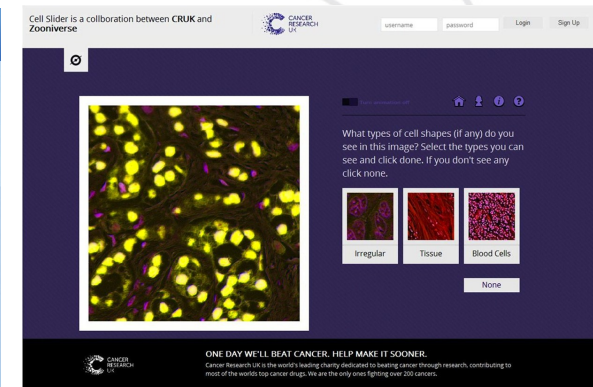
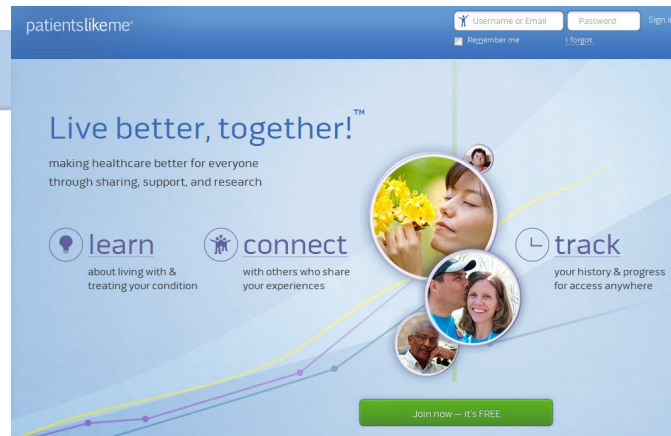
Donate your data for you, for others, for good.

Join now

Already a member? [Sign in](#)

What is data for good?

It's symptom, treatment and other health data that you choose to share on PatientsLikeMe. All that data helps you track how you're doing over time, helps the next person diagnosed learn what could work for them, and tells researchers what people really need so they can develop more effective treatments, faster.



MYELOMA CROWD RESEARCH INITIATIVE

SOLUTIONS FOR HIGH-RISK MYELOMA



May 9, 2015

"The first patient-driven campaign to find and fund critical research for high-risk multiple myeloma patients"

<http://mcri.myelomacrowd.org>

Ethics

- Making the most of data from research repositories, clinical records and patients requires a new understanding of concepts like 'science', 'personalised', 'ownership' & 'privacy'
- Managing the tense intersection between academic & commercial research remains a barrier, and the dividing line is often blurred
- Our social & policy research is seeking to establish the boundaries of the social contract and inform the wider data science agenda for the UK and beyond



Claudia Pagliari
Programme Director, MSc in Global eHealth at The University of Edinburgh

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Privacy, data science and personalised medicine. Time for a balanced discussion

Patient Record Access & Trust

Enabling patients to access and question their data may help to build trust in research, identify errors, and support trial recruitment

*Pharmacists asked us to identify controls, so I put the call out...I have 3000 patients with access to their records. When they know what they're sharing they have more trust. **It only took 6 hours to find the 80 or so patients that were needed!...**"The key was that patients had been carefully consented. If people know what they're signing up for and what the risks are, they won't be as inclined to fear it later" (Amir Hannan)*

 Harris Healthcare UK @HarrisHealthUK · Feb 26
Dr Claudia Pagliari #ehealthscotland says #patient portals key innovation to enable patient access to their records



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Computers in Biology and Medicine

journal homepage: www.elsevier.com/locate/cbm

Editorial

Understanding the evolving role of the Personal Health Record

Pincirolì & Pagliari (2015)



Claudia Pagliari
Programme Director, MSc in Global eHealth at The
University of Edinburgh

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Value of Personal Health Records for
Patients, Citizens & Science

Apr 19, 2015 | 171 | 12 | 7 | [in](#) [f](#) [g](#) [t](#)

Building capacity

- eHealth is multidisciplinary, multi-platform, cross-sectoral & global
- Rounded eHealth professionals are vital for future research, policy & practice



The screenshot displays the MSc Global eHealth website. The header features a dark blue banner with a satellite image of South America on the left, the URL www.eHealth.ed.ac.uk in the center, and the University of Edinburgh crest on the right. Below this is a red banner with the text "MSC GLOBAL EHEALTH". The main content area has a left sidebar with a red header "MSc Global eHealth home" and a list of links: eHealth, Benefits, Programme, Team, Postgraduate Professional Development, Fees and scholarships, Entry requirements, How to apply, Student testimonials, Mailing list, and News and events. The main content area has a breadcrumb trail: Home > School of Molecular, Genetic & Pop Health Sciences > MSc Global eHealth, and a "Contact us" button. There are four main content blocks: 1. "eHealth" with an image of four women and a child, and text stating eHealth is a priority area for international healthcare. 2. "Programme" with an image of a person at a computer and text about programme objectives. 3. "Register interest" with text about a mailing list. 4. "Applying" with text about online application.

www.eHealth.ed.ac.uk

THE UNIVERSITY OF EDINBURGH

MSC GLOBAL EHEALTH

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- Postgraduate Professional Development
- Fees and scholarships
- Entry requirements
- How to apply
- Student testimonials
- Mailing list
- News and events

Home > School of Molecular, Genetic & Pop Health Sciences > MSc Global eHealth

Contact us

eHealth

eHealth has become a priority area for the international healthcare sector and is attracting considerable global investment.

Programme

Find out about the objectives of our programme and the courses you can study for a certificate, diploma or masters degree.

Register interest

Join our mailing list to receive regular updates.

Applying

How to apply online.

Thank you

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Researchgate: www.researchgate.net/profile/Claudia_Pagliari

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